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Purpose. To understand the influence of Latino culture in breast cancer treatment, by developing a conceptual model of the informal support system utilized by 60 triads consisting of Latina cancer patients, their spouses/significant others and family/friends. Participants are drawn from the Breast Cancer Treatment fund, which provides payment for services for uninsured women.

Findings. The project has allowed a view into the role and function of the psycho-social support system. Not only does the support "team" assist with the diagnosis, treatment and consequences of breast cancer, it also helps the patient "connect the dots" of a disjointed system by negotiating, supplementing and extending services. Another key area of finding is that the supporting the spouse/partners has been neglected by the medical world. The loss of a breast does not seem to be as significant as the potential loss of a person key in creating a family.

Significance. A better understanding of how the psychosocial team functions to assist the patient in "connecting the dots" allows an understanding of where and how the services system does not reach into this population. Programs and policy at the individual and system level can emanate from the emerging conceptual model.

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INTRODUCTION

The purpose of this research project is to understand the influence of Latino culture on uninsured Latinas in breast cancer treatment, by developing a conceptual model of the informal support system utilized by sixty triads consisting of Latina cancer patients, their spouses/significant others, and family/friends. Participants were recruited from the Breast Cancer Treatment Fund, a private program that covers the cost of treatment for uninsured women with breast cancer.

The initial research plan was to interview four types of triads: 15 rural immigrant, 15 US born rural, 15 urban immigrant, 15 US-born urban. By the end of Year 1, we interviewed 33 women, mainly immigrant and rural. In year 2, the sampling protocol was modified, following suggestions from Technical Editor Judy Pawlus, to better reflect the fact that immigrant Latinas are far more likely to be uninsured, and hence to be represented in by Breast Cancer Treatment Fund, than U.S.-born Latinas. Her suggestions, was "not to control for rural or urban domicile and simply enroll the first 43 immigrants and 17 U.S. born subjects that qualify." From that time forward, we enrolled Latinas as their names were given to us by the Patient Care Coordinators of the Breast Cancer Treatment Fund. The subsequent enrollees were nearly all urban and nearly all immigrant. In fact, we were provided the name of only one additional U.S.-born Latina in the Breast Cancer Treatment Fund.

The sixty women were interviewed by the end of the project period and are comprised of fifty uninsured immigrants and ten US born uninsured Latinas. As this study is exploratory in nature and not statistically driven, the over-representation of immigrant Latinas among Breast Cancer Treatment Fund participants is not a major problem for the analysis. As detailed in the analysis section (Task 5) below, patterns will be described as they appear in the transcriptions. The immigrant patterns will be described in thick detail, given the predominance of immigrant transcripts. The U.S.-born patterns will be described in lesser detail, with fewer occurrences illustrating the major theoretical properties. This is an unavoidable consequence of the fact that the Latinas whose breast cancer treatment was paid for by the fund were overwhelmingly immigrants.

Open-ended interviews with an interview guide, rather than a standardized closed-ended questionnaire, were used in order to allow the triads to describe their social interaction in the face of a diagnosis of breast cancer. Topics probed in the interview guide included: familial responsibilities, information obtained regarding breast cancer detection and treatment, patterns of discussion and conversation regarding the diagnosis, experiences with control or lack of control experiences with fear or lack of fear, and experiences with health care providers. The interviews were conducted bilingually to preserve the code-switching that naturally occurs. The same interviewer, to preserve consistency and the quality of data collected, conducted all the interviews

Interviews were analyzed via a grounded theory process, which provides for identification and conceptualization of patterns in the responses of participants.

Unfortunately, the Ethnograph© software package that we were hoping to use to code the

transcribed interviews did not meet our needs when dealing with bilingual interviewees, so the coding of all transcripts for conceptual categories has been done manually. These categories have led to a conceptual model of the Latina breast cancer experience and can serve as a basis for program development in education and formal support-group development appropriate for a Latino population base.

Research Accomplishments for Each Task

Task 1: Finalize recruitment plan. Months 0-4.

This task was finalized in the first year, as of September 2000. Please see report dated September 2001 for details.

Task 2: Finalize Initial Interview Guide. Months 4-6

This task was finalized in the first year, as of September 2000. Please see report dated September 2001 for details.

Task 3: Identify and recruit sixty (60) Latina women diagnosed with breast cancer, their male partners and a friend and/or other supportive relative. Months 6-28.

Sixty triads have been identified, recruited, and interviewed. An unforeseen program change —but, for uninsured women with breast cancer, a welcome one —affected our ability to identify and subsequently interview all sixty Latina women diagnosed with breast cancer within the original time frame. This is explained below. Nonetheless, we have adapted to the change and completed the interviews, albeit with a time lag.

The Patient Care Coordinators of the Breast Cancer Treatment Fund program assisted us by referring potential research participants to us. This program was funded by the California Endowment (a private foundation resulting from a conversion of Blue Cross of California from a not-for-profit to a for-profit entity) to pay for treatment (initially 12 months, then extended to 18 months) for women who were uninsured at time of diagnosis and who were not eligible for any other form of insurance.

As detailed in our previous report (September 2001), recruitment was initially undertaken from January to December 2000, then suspended from January to the end of April 2001, while consent form issues were worked out. Copies of the Human Subjects Protocol and the Consent Form were appended to the September 2001 report.

Recruiting recommenced in May 2001 but was suddenly slowed down by a major change in Breast Cancer Treatment Fund administration. As of January 1, 2002, the Breast Cancer Treatment Fund program has been incorporated into the state's Medi-Cal program and is now offered as part of that program. This change from a private, non-profit program to a permanently funded state program is an advance for women of the state, as it is now part of the state budget. It did, however, cause disruption in the identification and recruitment of participants, which we have been able to overcome.

Task 4. Interview sixty (60) Latina women with breast cancer, their male partners, and a friend and/or other supportive relative. Months 6-30.

A total of sixty women were interviewed. Forty-six triads---the patient, a spouse/significant other and a family/friend--- were completed. Four women had only one other support person during their breast cancer experience, and these are classified as dyads. Ten triads were begun, but not completed, as the support network members interviews could not be successfully scheduled within the project time frame. See explanatory note under Conclusions below.

60 women interviewed:

46 triads completed (38 immigrant women and 8 US-born women)
4 reclassified as dyads because only one other support person was utilized (4 immigrant women)
10 triads not completed as support member interviews could be successfully scheduled (8 immigrant women and 2 US-born women).

Task 5. Analyze Data. Months 10-33

As detailed in the September 2001 report, the interviews have been transcribed in a bilingual format, to preserve the code-switching utilized by this population.

The major theme that has been seen in every triad is that of the informal support system helping the patient understand and deal with her breast cancer. The helping was seen in a number of ways: helping the patient with an individual provider, helping the patient overcome barriers in the medical care system, helping the patient as an individual deal with her breast cancer treatment. In each transcript, occurrences of the theme of helping the patient have been identified and marked. This theme is large enough and global enough that additional themes of a similar level were not needed for the analysis to continue.

Within that larger theme of helping the patient with her breast cancer, four major conceptual categories of helping that emerged are: assisting the communication with the doctor, dealing with barriers in the medical care system, cancer knowledge and comprehension, managing the personal impact of breast cancer. In each transcript, the occurrences of helping were re-coded as they fit within these four major conceptual categories.

The occurrences in each of the four categories were compared to one another, to see what each one revealed about the particular category of helping. A matrix of the types of helping was generated:

- Bridging the communication
- Navigating the medical care system
- Relating to cancer
- Absorbing the emotional shock.

The theoretical properties of each cell (each type of helping) were developed by continuously comparing the occurrences in each cell to one another.

Bridging the Communication Gap

- Bridging the language gap: functioning as translators between English and Spanish
- Bridging the conversational gap: facilitating the conversation flow when the patient-provider conversation flow is not functioning

Navigating the medical care system

- Paying for care
- Managing medical resources

Relating to cancer

- Bridging the information gap
- Bridging the comprehension gap

Absorbing the emotional shock

- The stigmatizing word. The very word "cancer" is stigmatized for these patients.
- Diagnosis shock. Pronouncement of a positive diagnosis of cancer can be quite an emotional shock.
- Presence. These patients, preferred not to function as autonomous, isolated patients but wanted others presence at key stages of the treatment process
- Motivating. Treatment options may frighten some Latinas. The ISN helps motivate them to continue the treatment.

As the categories of helping emerged, the interview guide was expanded to include probes about these specific areas.

The Ethnograph© program proved not to be useful for a bilingual sample that utilized code-switching (shifting between Spanish and English) in their normal conversation. Therefore, coding has been done manually.

Task 6. Create a Theoretical Model. Months 30-36.

The categories and their theoretical properties have been developed into a model of "cultural literacy for humanistic medicine" that can be used for the education of medical students about cultural competency with this population. Cultural literacy requires the mastery of symbols and their underlying patterns by the concentrated study of a content area. Humanistic medicine requires a provider to be empathetic and able to understand a patient's narrative. This model of cultural literacy is set within the context of debates within medical education about humanizing medicine and developing cultural competence in future physicians. In this case, the content area is uninsured Latinas with breast cancer. The patterns seen above (bridging the communication gap, navigating the system, relating to cancer and absorbing the emotional shock), symbolized by our labels,

help the student better understand the world experiences of uninsured Latinas coping with breast cancer.

Our analysis is, in part, a substitute for concentrated content area exposure. By "pre-digesting" the patients' narratives, as set forth in our sixty triads, we can condense the time needed for a student to create a therapeutic alliance with uninsured Latinas with breast cancer by understanding how their informal support systems help them understand and deal with their breast cancer.

Task 7. Write up findings and disseminate findings, months 32-36.

To update the researchers with literature published subsequent to the proposal write-up, we have updated our review of the literature on Latinas and cancer, as well as on cancer and support systems. In addition to these reviews, we have conducted two new literature reviews. The new reviews were in the areas of humanistic medicine and cultural competency training for health care professionals and medical students.

A working draft of the paper "Cultural literacy for humanistic medicine: Latina breast cancer patients define cultural competency" has been written and circulated to colleagues for comments.

Comments have been received and integrated into a second draft of the paper.

Paper will be submitted to Academic Medicine for review, with a view towards publication.

CONCLUSIONS

The conclusions are presented below in three areas: Methodological, Analytic, Action Research.

Methodological Conclusions.

Need for Interviewer Consistency. The more highly structured the interview, the more the consistent the participants' responses become, as their choice of response is limited by the structure. This project took the opposite approach: as not much was known about the topic (the informal support network), the data collection was purposely open-ended with low structure. In a way, the interviewer was the structure, as she worked with the participants. This approach has its drawbacks.

Largely low-education, low-literacy, low-income immigrant Latinos were asked to participate in open-ended interviews to better understand how their informal support networks functioned. With only probes from the interviewer, the participants were allowed to narrate their experiences in their own words and on their own terms. In essence, they were allowed to manage the interview, moving at their own pace as they recalled events in their life histories. Tangents were nearly inevitable, as their memories

gradually focused in on their experiences. In order for any consistency to be developed in the interviews, the same interviewer was used for all interviews. A public health nurse with nearly fifteen years of research experience, the interviewer was able to hear all the participants and discretely probe them to cover areas that needed to be covered. While it might have been more time-efficient to have more than one interviewer, the consistency between the interviews would have been lessened, if not lost altogether with three or more interviewers.

Interview time recorded per audio-tape ranged from a minimum of 90 minutes to a maximum of 180 minutes. Between 16 to 18 hours of staff time is needed to transcribe each 90 minute tape, adding up to over 2,000 hours of staff time for transcription.

Complicated Lives Complicate the Research. The expected stresses of dealing with breast cancer were emphasized in this low income, low education, low literacy population. These emphasized stresses entered the research process in the following ways:

- **Requests for Assistance.** Respondents often asked the interviewer to assist them in various ways, including translating forms for them, helping them fill out forms, and helping them seek information,
- **Family Interruptions.** The needs of the family members (including those who were also part of the informal support network) complicated the research in two ways. The first was in the scheduling of interviews. Low-income people lead economically insecure lives, and their pursuit of short-term jobs leads to a high degree of residential mobility. The second was that of family issues, which extended beyond the US border. Trips to Mexico to resolve family issues were common, resulting in broken appointments and irregular, unreliable re-scheduling. These family and economic complications were the principal reasons why some triads were not completed; in spite of repeated visits and rescheduling, the remaining triad members could not be pegged down for an interview, in spite of many promises to the contrary.
- **Need to "Desahogarse" (unburden self).** Once a rapport was established with the respondents most of them wanted the interviewer to hear their unburdening. This ranged from simple observations about the breast cancer experience to comments, even complaints, about the treatment process.

Analytic Conclusions

Code Switching Complicates Analysis. While the respondents were primarily Spanish-dominant, they all exhibited a certain amount of "code switching", *i.e.* use of both Spanish and English during an interview. The amount of code switching can vary from the inclusion of a few words in English, to the use of entire phrases in English, to an alternation between sentences and/or paragraphs in English and Spanish. The P.I. originally used a qualitative software package, Ethnograph, in an attempt to speed up the

analytic process. Yet, the software, which is based on word recognition, was completely unable to handle the code-switching contained in the transcripts. Furthermore, the respondents' accounts of their experiences frequently did not possess a linear narrative but were episodic and disjointed, and the Ethnograph software was not able to process them adequately. As a result, the P.I. had to revert to hand-coding the data, and was not able to realize any time savings by use of a pre-packaged program.

Action Research

End Use of Research Not Clear to Respondents. One portion of the Human Subjects Consent form is supposed to describe the end use of the research: "Your participation can help us better understand how breast cancer affects Latinas, their spouse and/or male partners, and their family (relatives). This understanding can help health administrators and providers develop and provide more culturally competent care to Latinas diagnosed with breast cancer and their families." While the meaning of these phrases was clear to the Human Subjects committee at UCLA, often it was not clear to the participants, who expressed interest in knowing concretely how the research they participated in would help. The interviewer had to expand on the wording, to describe that articles would be written to be published in medical journals. Physicians and other health professionals would read the articles and know how to take better care of Latina patients.

Ignorance of Lymphatic system. After the first quarter (approximately) of the interviews were completed and analyzed, a pattern emerged: even after all their experience with breast cancer, the low-education, low-income, low-literacy Latinas could not express knowledge of the lymphatic system. Increasingly, the interviewer began to probe specifically on knowledge of this important area. Most of the participants she probed (the majority, but not in a quantified way) were not able to describe the lymphatic system. Even though the analysis was not complete, this lack of knowledge was deemed important enough to pass onto the Patient Care Coordinators in the Breast Cancer Treatment Fund.

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KEY RESEARCH ACCOMPLISHMENTS

60 women interviewed. The Patient Care Coordinators who linked the women with the Breast Cancer Treatment Fund initially identified and solicited participants to be included

in this study. Some women changed their minds about participation between the time they had agreed to do so with the Patient Care Coordinators and the time the project interviewer contacted them, so more than 60 women had to be contacted. By the end of the project, 60 women had been interviewed. The remaining members of each triad likewise had to be identified and their agreement to participate obtained.

Coding. All transcriptions have been coded for Level 1 analysis (reading for general themes). A team of two staff members (including the PHN interviewer) was trained to code the transcribed interviews. Approximately 2,500 hours of staff time have been devoted to Level 1 coding.

Level 2 and 3 coding (analysis and comparison of themes) has been completed to date on 32 of the completed triads. Approximately 500 hours of staff time have been dedicated to Level 2 and Level 3 coding.

Paper Prepared for Submission to *Academic Medicine*. The manuscript titled "Redefining the Standardized Patient to Teach Cultural Competence: The Standardized Latino Network" was prepared, circulated for comments, and modified on the basis of the comments. As a result of the feedback, the original manuscript was modified substantially. Please see the current version in the Supporting Data/Appendixes section.

Themes for Additional Analysis. The data set developed is very rich in sensitizing material. While the first paper prepared deals with the ways in which the informal support system assists the patient in developing knowledge about breast cancer and its treatment, a number of other problem areas emerged that will be included in subsequent papers. These include:

- The role of the adult child
- The male partner's need for psychological counseling
- The couple's need to discuss sexuality and depression with the physician
- The management of sadness and depression by the informal support system members
- The development of different coping styles (e.g., upbeat coping, religious coping, etc.) by the support system

REPORTABLE OUTCOMES

In-Service Training Pamphlet. At the end of Year 1, an in-service teaching aid was developed to assist providers in better serving their Latina clients. This material was reviewed by the California Health Collaborative (the entity then administering the Breast Cancer Treatment Fund program, which provided the participants for this study).

Poster Session. A poster presentation of the project was developed and presented on October 19, 2002, during a session of the Era of Hope meeting in Orlando, FL.

Medical and Pre-Medical Curricula. The conceptual model of the informal support network has been included as lecture materials in the curricula of three different courses taught by the P.I.: Medical Education 315 (UCLA), a first-year elective on Latino health;

Public Health 106 (UCLA), an upper division course taken by many pre-medical students; and Public Health 6 (UCLA and community colleges), a lower-division course for students contemplating declaring pre-medical majors. This last course is also taught at community colleges in the area (Cerritos Community College, East Los Angeles City College) to prospective pre-medical students.

Publishable paper. The first publishable paper from the research targeted the readers of *Academic Medicine* as its audience. The research findings, the P.I. felt, would be most widely disseminated in a journal devoted to the teaching of medical students. An early draft of a publishable paper was sent out for comments by colleagues. These comments have been incorporated in the version submitted, titled "Redefining the Standardized Patient to Teach Cultural Competence: The Standardized Latino Network."

Supporting Data/Appendices

Appendix A: Draft of the paper "Redefining the Standardized Patient to Teach Cultural Competence: The Standardized Latino Network."

Appendix B. Copy of the Consent Form.

Appendix C. In-service training material, the pamphlet "Fifteen women and their families help us understand breast cancer" (also appended to the First Annual Report).